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ITCHING TO KNOW MORE: OVERCOMING BARRIERS TO SUCCESSFUL MANAGEMENT OF ATOPIC DERMATITIS

Case A.R.

You're seeing a 5-year-old girl along with her mother, referred for hard-to- control eczema. Mom reports this has been "life-long". She moisturizes her daughter's skin regularly but doesn't think it makes much difference. She finds the topical steroids that have been provided work "a bit" but never really seem to clear the eczema and she's quite reluctant to use them as many people have told her she shouldn't use them if not needed. She'll use them when the eczema is really bad. Sometimes the eczema is "okay" and she'll only be up at night a few times a week but when it's really bad she can be awoken two times a night with pruritus. Mom and dad work in shifts and their schedules change frequently. Mom feels she is constantly "chasing" the eczema. What she hopes to get from the consultation with you is a way to stop the eczema "once and for all". You note on exam that the daughter has moderate eczema over 70% of her body though her face is clear; the girl is also fidgety and restless.

BACKGROUND

Patients suffering from atopic dermatitis ("eczema") are frequently referred to specialists for management advice. Different published guidelines and management recommendations for eczema typically share a common goal of helping health care practitioners (HCPs) provide patients with strategies to control their eczema and include 1) trigger reduction, 2) emollient use, 3) topical anti-inflammatory medications, 4) treatments for complications and 5) ancillary treatments.[1]

While it is encouraging that emerging systemic therapies may change eczema management in the future, currently, for many patients, topical treatments remain the mainstay of therapy.

Many patients remain **sub-optimally** controlled--not because of a lack of good strategies—rather, due to barriers in executing these strategies successfully. The focus of this article will be to help identify and overcome some of these common barriers that might impede treatment management success.

BARRIERS TO SUCCESSFUL TREATMENT MANAGEMENT

Table 1 provides a framework of questions to identify barriers to optimal eczema control.

1. Does the patient (or patient's parent) **understand** the treatment management plan?
2. Does the patient (or patient's parent) **accept** the treatment management plan?
3. Is the patient (or patient's parent) able to **implement** the treatment management plan?

Table 1 Questions to identify barriers to optimal eczema control; courtesy of Miriam Weinstein, MD

1. DOES THE PATIENT UNDERSTAND THE TREATMENT MANAGEMENT PLAN?

Increasingly it is recognized that education about eczema and therapy significantly enhances the efficacy of disease management. The literature on therapeutic patient education (TPE) in eczema has grown considerably in the last decade and the education is itself considered part of therapy.[2] However, there are many potential barriers to patients increasing their health literacy around eczema.

Confusion for the patient as new information is added

Patients often have misinformation, conflicting information, gaps in information and too much information that can be overwhelming. This can create confusion if not addressed by the clinician who is able to better guide patients to reliable sources of information that will avoid such situations.

Unique learning needs

Patients vary in the amount and type of information they need to effectively put management strategies in place. Furthermore, patients differ in learning styles, for example, auditory versus visual leaners. Differences in cognitive skills, memory and processing information will also impact information acquisition and understanding. These individual needs preclude a "one size fits all" approach to educating patients.

Cultural and language variations

Non-verbal communication may have different meanings culturally and could impact comprehension. Spoken language can be filled with nuance, idioms and jargon and can be confusing. Modern day access to online translation software such as Google Translate can help in situations where English is not the first language for patients and their caregivers.

Situational impacts

Patients can experience fatigue, distraction and difficulty concentrating which may impact how information is received.

2. DOES THE PATIENT ACCEPT THE PLAN?

Even when information is successfully understood, there can be significant potential barriers to gaining patient acceptance to the proposed plan.

Trust not yet established

Patients bring information with them from their own trusted sources and established relationships. The specialist may have to earn the patient's trust before advice will be accepted. This is a challenge in a time-limited consultation. Some sources of information that are important to patients may include primary care physicians, pharmacists and other specialists. Many patients seek advice and treatments from complementary healthcare practitioners and have different beliefs about health and health care practices.

Family, friends, coworkers, and peers are common sources of information, with advice sometimes being provided in an unsolicited fashion. Different media sources and the internet are also frequent sources of medical information.[3] Despite the lack of accuracy, utility, and relevance of much of the accessible internet information, many consumers are unable to appropriately distinguish between high-value and low-value online health information.

Steroidphobia

Fear of topical corticosteroids is extremely prevalent among patients, families and also health care practitioners. Fear of steroid side effects has been proven to **negatively** impact adherence to therapy and, thus, outcomes.[4]

Focus on food allergies

Often thought to be the cause of the disease itself or the cause of flares, food allergies are best thought of as a co-morbidity rather than a directly provocative cause of a flare. Certain foods, as a source of health issues, and the withdrawal of certain foods as a remedy for health problems are often strongly held beliefs by many and supported strongly in the lay media. It may be confusing as many patients have both conditions and both food allergies and eczema cause pruritic rashes—urticaria and dermatitis, respectively. Further complicating the interpretation of food reactions is that certain foods - usually acidic foods such as citrus-based foods - act as an irritant, not allergic trigger for a flare of eczema.

Patient's perception of value in eczema management

Often patients hear messages that trivialize their experience of eczema. Phrases such as "just eczema" or advice to use treatment only when "really needed" or a focus on the eventual improvement with time may cause patients themselves to minimize their disease and undermine the value of therapy.

3. IS THE PATIENT ABLE TO IMPLEMENT THE PLAN?

Even with patient understanding and acceptance of a treatment management plan, hurdles may remain in the implementation of a successful treatment plan.

Components of management plan

Complex plans with multiple steps or actions such as different medications for different stages of a flare and complicated plans with tasks that may be difficult to complete such as bleach baths and wet wraps can be barriers to successful management. While "straightforward" to those of us who suggest such strategies daily, this may not be the case for patients. Patients may find it easier to avoid tasks that are too complicated or complex. Therefore multi-step strategies such as bleach baths –particularly when the evidence for its utility is equivocal --may best be reserved for select patients in whom optimal first-line management is insufficient for control.

Costs

There are important non-financial costs to consider as patients expend significant time, energy and effort on management plans and failure to consider these burdens in selecting treatment management strategies can pose barriers to achieving desired outcomes. Some patients truly desire to see their skin improve and understand how to get there but feel that the tradeoffs may not be worth it. They ultimately accept living with suboptimal control as the "price" to pay. However, treatment management plans can be altered to lower these burdens and improve outcomes.

Application of topical therapy

A common assumption dictates that patients will know where, when and how to use their medications. This false assumption is an under-appreciated barrier and one of the easiest to address. Like any "tool", patients need to know where, when and how to use topical therapy. A starting point is to be able to identify where there is active eczema, and this can be challenging for patients (**Table 2**).

CHALLENGE	FEATURES
Eczema can present with many morphologies	e.g., classic dermatitis, lichenification, excoriations etc.
Associated skin finding may be hard to distinguish from eczema	e.g., keratosis pilaris, follicular prominence etc.
Variation in prominence of eczema	range from visibly obvious to very subtle rough patches only appreciated on palpation
Some perceive mild-moderate eczema as "normal" and only a worsening is called a "flare"	chronic patches/plaques of active eczema thought to be normal
Eczema may present only as pruritus	skin looks and feels normal but is itchy

Table 2. Challenges to identifying active eczema; courtesy of Miriam Weinstein, MD

Patients often don't know when to use medications and thus will use them with less-than-ideal frequency and duration resulting in mild-to-moderate improvements in symptoms such as rash and itch but never the clearing of a flare completely (**Figure 1**). The patient may not connect the sub-optimal use of medications with sub-optimal outcome and control. The patient's perception is often that the medication simply doesn't work, and they seek a different medication. Prescribing a different medication—without knowing where, when and how they used the "failed" medication—may beget the same problem. In patients with predictable areas of flare-ups, an additional preventive strategy to daily moisturization, could be 2-3 times weekly application of a topical steroid or topical calcineurin inhibitor to suppress new flares from developing.

How patients apply medications can impact outcomes. Sparing use of medications rather than adequate use or the mixing of medications with moisturizers to save time---which dilutes the intended potency of the medication—are common strategies that undertreat the eczema.

Strategies to overcome barriers

Challenges impacting health literacy—the ability to access, understand, accept and utilize information to manage health—can be overt or hidden and thus all patients should be provided with treatment management plans that ensure barriers are identified and minimized.[5]

1. PROMOTE UNDERSTANDING OF THE MANAGEMENT PLAN

Just the facts. Keep information simple and recommendations based on evidence. Some aspects of dermatologic dogma are often suggested but not well substantiated in the literature. For example, despite many firmly held opinions on bathing techniques, the literature lacks evidence supporting specific advice regarding bathing.[6] Similarly, there is a paucity of data supporting many of the laundry practices often suggested.

Less is more. Disease state and treatment information can be built "in layers" beginning with the basic concepts and adding information if that patient needs/wants more. If the volume of information provided causes confusion, mental fatigue or overwhelms the patient then successful disease management may be hindered. Use simple, clear, lay language. Use diagrams and photos to represent concepts or to reinforce discussion points (e.g., models of the barrier defect; photos showing different morphologies of eczema, etc.). Written action plans as a take home reminder of the patient's plan have demonstrated utility in eczema management.[7]

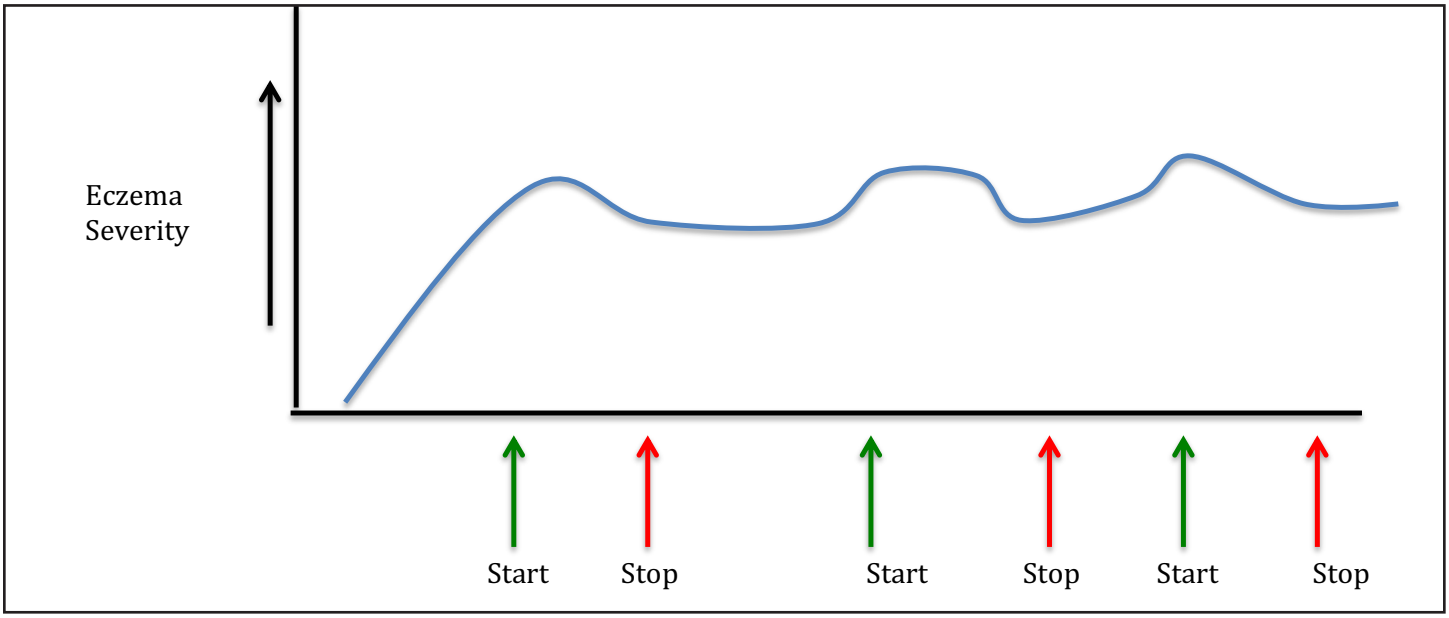

Figure 1. Common treatment pattern: treat only as flare gets "really bad"; eczema in chronic flare; never clear.

Check in and Follow up. It is important to be mindful that cultural and language differences may impact perspective, interpretation and understanding. Therefore, periodically "checking in" to ensure comprehension is important. It is also critical to provide opportunities for patients to ask questions or clarifications as some patients do not feel comfortable interrupting a physician even if needed. It may also be of value to offer interpreters when indicated.

Read the room. Distractions, fatigue, and trouble concentrating will greatly impact information uptake. Physicians should observe for loss of eye contact and attention; patients looking at their phones, parents turning attention to children's needs or patient disinterest. Physicians may also consider providing information over several sessions if it is too much for one session. It is imperative to repeat key information multiple times.

2. ENHANCING ACCEPTANCE OF THE PLAN

New kid on the block. A new specialist won't yet be a part of the patient's cadre of trusted sources of information. A specialist may be well-intentioned and armed with an excellent care plan but without "buy in", it won't be used. Trust can be a challenge to build in a short time, but some strategies can help. Avoid a paternalistic tone in favour of a collaborative approach. While it is critical to offer corrections to mis-information, it is important to do so without being dismissive of their valued sources. If there are concerns about their particular practices, state why there is a concern and help them put safeguards in place if they plan to continue these practices. For example, if a patient is going to use dietary restrictions as a strategy, though you haven't advised this, suggest they see a nutritionist to ensure their plan won't negatively impact their health. If a patient relies on the internet, identify sites that use vetted, reliable information; advise patients to check the sponsors of the site and to be wary of sites with ads or those that sell products along with providing information.

The elephant in the room. "Steroidphobia" exists for many patients even if they don't voice the concern and thus should be assessed in all patients. A useful validated tool to assess steroid fears is TOPICOP©.[8] While side effects such as atrophy and absorption are real side effects of topical steroid use, their risk of occurring with optimal usage is rarer than many appreciate.[9] Risk can be a challenging concept for patients to understand. Analogies from everyday life where risk exists but is low may be helpful in providing context and appropriate frames of reference for patients. There is a widely-held belief that if steroids are used too much they will lose their efficacy. Tachyphylaxis has not been well-established with topical steroids for eczema and failure to respond may represent under-use, not overuse.[10] Living with untreated or under-treated eczema often produces more frequent and more profound side effects than those from medications (**Table 3**).

Sleep disruption for patient and family
School/work negatively impacted (attendance and/or performance)
Self-esteem negatively impacted
Socialization negatively impacted
Sexual/intimate relationships negatively impacted
Sports/activities disrupted
Staph aureus/Streptococcus/HSV infections

Table 3. Potential side effects from untreated or under-treated eczema; courtesy of Miriam Weinstein, MD

"People don't care how much you know until they know how much you care" Patients need their experience with eczema and its impact on their lives acknowledged and validated as being worthy of treatment. It is not a trivial disease for many. Data abounds on the negative impact that poorly controlled eczema

can have on quality of life.[11] Patients may need "permission" to treat their disease and be empowered with knowledge and strategies to control their disease as would be offered with other chronic illnesses, but which may be provided reluctantly or with reservation in the treatment and management of eczema.

3. SUPPORTING IMPLEMENTATION OF THE PLAN

If you build it, they will come. Clinicians should strive to build plans that are as simple and basic as possible so that patients can easily adopt them. Could one medication be used instead of two different ones? Is every step in the plan necessary? Every single action being asked of a patient should have a value-added benefit. If a step may not have significant impact on outcomes, then clinicians should reconsider if it is needed. For example, antihistamines are often advised but with little support in the literature for their utility.[12] Sedating antihistamines have been used in the past to help reduce nighttime sleep disruption from pruritus, but a more effective strategy is to adequately and completely treat all active areas of disease, and thus the source of the pruritus

Teamwork makes the cream work. It's important to work collaboratively with patients when developing plans so that we know what costs they are willing to incur. Management plans require patients to expend their time, money and effort and clinicians cannot effectively choose treatment plans without knowing what patients value. A desired outcome may be achievable with a milder medication dosed more frequently or a stronger one dosed less often. An ointment might be a better choice in a given situation but if a patient won't use it, could a cream work instead?

Add a demo to the memo. In addition to a written action plan, try demonstrating where and how to apply topical therapy—which may not be intuitive for many. In order to know when to treat, one must first know what constitutes active disease—i.e., where to treat. Clinicians should take care to point out active eczema, different morphologies, different severities and unaffected skin. It is important to ensure that patients understand that itchy skin-even in the absence of the rash- is active eczema and should be treated. Have some jars/tubes of un-medicated creams and ointments to demonstrate how much to use and how to apply. The Finger-Tip Unit can be a useful strategy for medications dispensed in tubes.[13] Ensuring that patients know when to treat—ideally from the start of a flare until clear skin --can be demonstrated and shown with a graph (**Figure 2**).

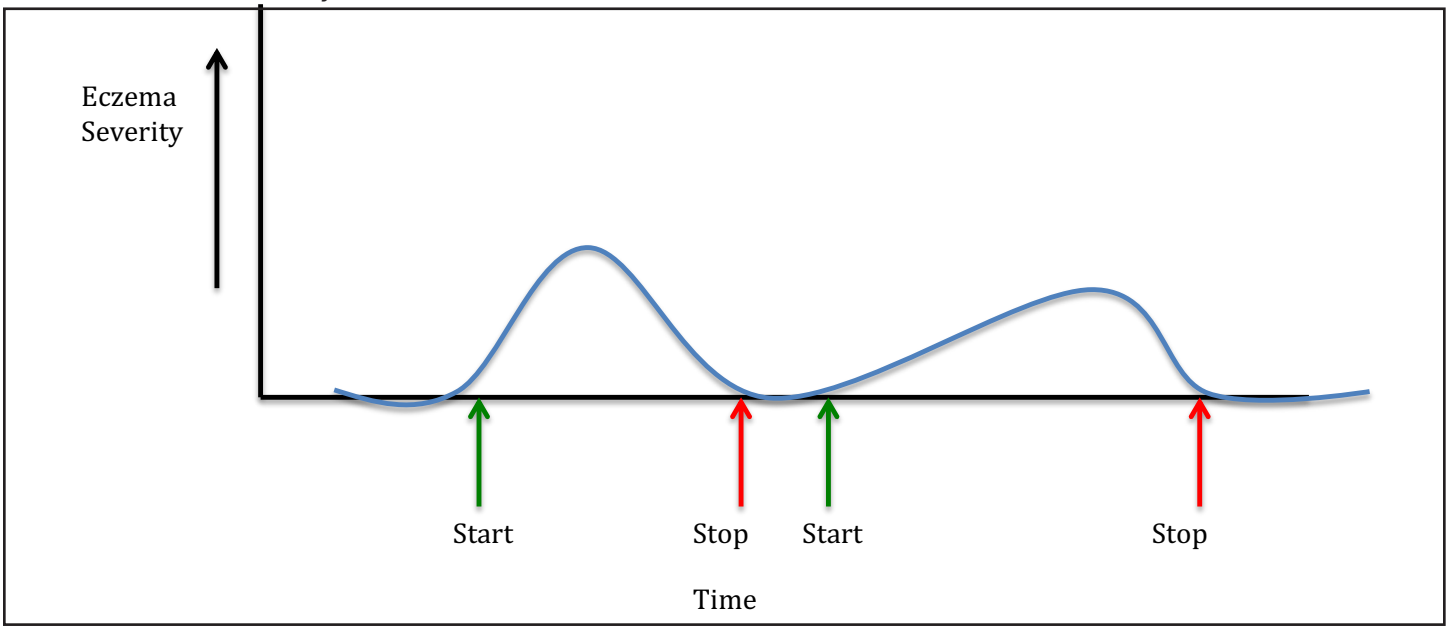

Figure 2. Optimal treatment pattern: treat as soon as a flare starts until it has resolved; eczema clears between flares

For patients unable to achieve adequate control with proper use of first line therapies or for those unable to implement such strategies successfully, consideration should be given to systemic agents. Currently, this includes phototherapy; the off-label use of such agents as cyclosporine and methotrexate or dupilumab which is a biologic agent targeting IL-4/IL-13 and is approved in Canada for patients age 6 and above.

Let's now turn our attention back to patient A.R. who is suffering from chronic, significant eczema. Assessing for potential barriers while developing a management plan and employing strategies to mitigate these barriers should increase the plan's efficacy (**Table 4**).

CONCLUSION

Eczema is not curable but there are established, effective management strategies that can bring about excellent control. Many patients can be managed successfully with topical therapy. Ensuring patient understanding and acceptance of treatment plans with support from their healthcare team will best overcome the many barriers impeding control to lead to improved quality of life in these patients.

POTENTIAL BARRIERS	POSSIBLE SOLUTIONS
Incorrect information about expectations of management	Provide info about remitting/relapsing nature; stopping eczema "once and for all" not a realistic goal; treating flares is realistic
Child is fidgety and restless	Keep information simple; watch for distraction; provide information over multiple sessions
Steroidphobia	Explain when used properly, risk of side effects are rare; impacts of disease are a greater risk
Minimizing impact of disease	Sleep disruption is significant; acknowledge this is a significant impact on quality of life and a disease worth treating
Underusing medication	Explain that using medications to all active areas until clear will promote remissions between flares rather than treating just when "really bad"
Potential time factor in application of medication	Shift work for parents may make multi-step plan complicated; consider 1 medication of adequate strength b.i.d. at times that work for family

Table 4. Management plan for A.R.: Potential barriers and possible solutions; courtesy of Miriam Weinstein, MD

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